CHAPTER 1

History, Context and Language

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This first chapter sets the scene for the chapters to follow. It provides an introduction to the context as well as the history and cornerstones of service user research and service user involvement in research as an evolving discipline. It provides examples which typify the different starting points from which service user involvement in research originated. Examples are given of how and why service users became researchers and the different types of research service users have been, and are being, involved in. There is a brief examination of the politics of research, and how governments are both encouraging involvement and creating further hurdles for service users to overcome. The chapter gives an introduction to the terminology used to describe service users in research, together with the background and history of the respective terms.

INTRODUCTION

Service user involvement in any aspect of mental health must include the possibility that involvement will lead to real change. As the subsequent chapters of this book will demonstrate, service users and survivors of psychiatry have sought to challenge and change the underlying assumptions and world-views on which traditional mental-health research are based, in small, incremental ways and in radical, fundamental ways. This opening chapter sets the scene for the rest of the book by describing the origins of service user involvement in research in the UK, the US and Canada, a few of the countries where involvement in mental health research has taken hold.

Service user involvement in mental health research would not have happened but for the efforts of survivors and users. Power-sharing is rarely initiated from the top, though the contributions in this book also give due credit to the help that political and professional allies have provided.

Service users have, of course, always been involved in research as subjects of tests and as respondents to questionnaires, but it is only in the past 20–25 years that they have been
invited in as partners, and have taken part in planning, designing, and carrying out research along with professionals, or as researchers in their own right. This is a new area of development, which has come from a number of different starting points, as this chapter will show.

Although service user groups were active from the late 1970s onwards, for some years they made few inroads into the area of research. Perhaps, in the first ten years, research was not high on the agenda for service user organisations. Primary concerns were providing mutual support and information to their members and campaigning for better services and better public understanding of mental health issues. The world of research was inaccessible to all but clinicians and academics, and the rules of engagement in research were not service user-friendly. Dworkin (1992), in her book *Researching Persons With Mental Illness*, makes no mention of involving the persons being researched in any way, and describes the difficulties of placing reliance on patients’ answers to questions, given their illness. In some ways, the 1990s marginalised the nascent service user movement even more firmly than it would have been ten years earlier, as Dworkin shows that in the US at least, mental health was moving away from an earlier public health model and refocusing on the biomedical model. This was reinforced when ‘the 1990s were declared the Decade of the Brain... with emphasis upon basic neuroscience research’ (p7). Though aware that mental illness diagnosis is controversial, Dworkin advises that researchers ‘can ill afford to ignore diagnostic issues’.

Though in the late 20th century there was small chance of involving service users in mainstream medical research, there were other forms of research, such as policy-oriented participatory-action research, and service evaluation, concerned with providing high-quality services in the community, where service users/survivors could, and did, get involved and gain experience. Also, as Beresford points out (Chapter 13) user-led research ‘has the longest history of any form of user involvement in research’ – service users could, and did, begin their own small-scale studies individually and in groups. This type of small-scale study and evaluative, policy-oriented research did not, and still does not, command the status and funding that is given to brain biochemistry, genetics, and drug trials.

Between ‘pure’ laboratory-based research and ‘applied’ research such as service evaluation, there has traditionally been a hierarchical division. Some have argued this to be a kind of class distinction, where ‘pure’ research was carried out by university-educated intellectuals, while messy, real-world, applied research was left to practical-minded working-class engineers.

Rather than a comprehensive history of the origins of involvement in research, we will point out some examples which typify the different routes by which service users and survivors developed skills and confidence and made alliances with professionals which began to create the basis for the establishment of service user involvement.

**STARTING POINTS FOR INVOLVEMENT IN RESEARCH**

**Origins of involvement in research**

The origins of involvement in research mirror the origins of the service user/survivor movement generally. They began with efforts by individuals and groups to make sense of their experience, reclaim their identity and have a say in the mental health world. Most of
the involvement examples in this book show that it has been the result of people’s actions on their personal and collective journeys towards empowerment. For instance, some service users/survivors have found their way into research through their efforts to change things so that others will get a better experience than they did.

**Individuals making sense of their own experience**

A US example is the work of an individual, Leonard Roy Frank (1978) who researched and compiled an anthology of information about ECT. In testimony, Frank (2001) described his reasons for starting his research on ECT:

> In 1962, three years after moving to San Francisco, I was diagnosed as a ‘paranoid schizophrenic’ and committed to a psychiatric institution where I was forcibly subjected to 50 insulin-coma and 35 electroconvulsive procedures. This was the most painful and humiliating experience of my life. My memory for the three preceding years was gone. The wipe-out in my mind was like a path cut across a heavily chalked blackboard with a wet eraser. Afterwards I didn’t know that John F. Kennedy was president although he had been elected three years earlier. There were also big chunks of memory loss for events and periods spanning my entire life; my high school and college education was effectively destroyed...

> Following years of study re-educating myself, I became active in the psychiatric survivors movement... In 1978 I edited and published The History of Shock Treatment. Over the last thirty-five years I have researched the various shock procedures, particularly electroshock or ECT, have spoken with hundreds of ECT survivors, and have corresponded with many others. From all these sources and my own experience, I have concluded that ECT is a brutal, dehumanizing, memory-destroying, intelligence-lowering, brain-damaging, brainwashing, life-threatening technique.

Many other survivors/service users have begun their research similarly, including one of the authors of this chapter, who found Frank’s (1978) book in 1985 in a left-wing bookshop. It helped her along her own path to recovery and to use her own experience of ECT as the starting point to a new career as a researcher and writer. Wallcraft carried out a small study of ECT patients’ stories as part of her degree (1983–7), and later did a PhD thesis based on narrative first-person accounts of first experiences of breakdown and hospitalisation. Lindow (1990) and O’Hagan (1994) are two other survivors who became academics and researchers as part of their own journeys to mental health activism and recovery.

**Service user/survivor groups funded to do consumer studies**

While some US survivors began their research, like Frank, as individual pioneers, others chose to work in groups, developing participatory methods. Some of those who developed these methods throughout the 1990s (Van Tosh, Ralph and Campbell, 2000) pay tribute to earlier work, such as the 1984 People First study in California where people with learning disabilities were enabled to talk about the services they needed, and a methodology was developed to use their contributions. The Hill House Project in Ohio was another example, where people labelled ‘mentally ill’ helped to design the research instruments proved to be
reliable and valid, and demonstrated that consumer members had the expertise to identify and classify their feelings (Prager and Tanaka, 1979; Smith and Ford, 1986).

One such was Dr. Jean Campbell (see also Chapter 9) who was principal investigator of the Well-Being Project, which ran from 1986–1989. This was an influential survey programme, based in California, which identified the factors that helped and hindered well-being of those labelled mentally ill. The interviewers were all service users, trained as part of the programme, and carried out over 500 face to face interviews, producing a report (Campbell and Schraiber, 1989) a video documentary, a compendium of statistics, oral history, art and writings.

A Canadian example of local activism as a starting point is the setting up of Second Opinion Society (SOS) in 1990 in Whitehorse, Yukon. As Sartori (2007) recounts, she and two other psychiatric survivors set up SOS in response to their dismay with media portrayals of the ‘mentally ill’. The following year, they were funded by the Yukon Ministry of Health to carry out a needs-assessment survey of what psychiatric survivors needed most.

With a good deal of help and support from allies in the Yukon government, SOS completed this study, which was a tremendous learning process for the group, as Sartori (1997) relates in an earlier article:

> The amount of work involved was enormous. For a long time, I felt that it was a mistake to have taken on this project. We’d never done anything like it, so it was this big, big thing that hung over our heads and took our energy away from our other work. I almost wanted to give up. But the wonderful Statistics Department people who were helping us kept telling us this would be important. And, looking back now, they were absolutely right. It took twice as long as we thought it would, but it gave our group a really good foundation. We had the voices of Yukoners and we could say, ‘Here, this is what people want’. It gave us a lot of credibility.

(pp 126–7)

SOS’s success was not without opposition, according to Sartori (1997):

> There was a huge outcry on the part of people in social services and in the medical profession. For example, the medical council wrote letters to the editor saying things like, ‘How dare they let this group interview other people who have experienced the psychiatric system? They’ll all jump out of the window!’

Not only did this work give SOS a solid basis of experience and credibility from which they have operated ever since, but their work was recognised by the Federal Health Promotion department as one of the best participatory research projects that had ever been done in Canada.

‘Insiders’ – professionals with service user experience

Another form of starting point for involvement in research was from the inside of establishments and organisations, from those who were current or former service users/survivors as well as paid workers and professionals. Some were academics, others were mental health professionals, such as nurses, psychologists and doctors, or managers and politicians. They shared a wish to narrow the gap between their personal and working lives and put their experience to good use. Some of these people may have been attracted to their profession
because of an earlier mental health problem, others had a breakdown during their working life, sometimes because of the stresses of the job.

Such individuals, such as Dan Fisher, whose chapter is included here (Chapter 16), have contributed tremendously to the establishment of service user involvement in research, as researchers and as allies to service users and user groups.

Reformers in state and non-profit organisations

Service user/survivor involvement in clinical research and large-scale funded community/social research would not be possible without the work of committed people in government and the large non-profit organisations. They have responded to the rise of organised service user/survivor groups by inviting individuals and groups to join decision-making committees, or have formed partnerships with service users to bid for research grants, or been generous with their knowledge, expertise and contacts. There are many examples of this help offered to service users/survivors throughout this book.

In the UK, we have the example of the setting up of Involve, a state-funded organisation to encourage and support service users to be involved in research. This was originally called Consumers in NHS Research, and was set up in 1996 by the Director of Research and Development in the NHS. It aims to ensure that consumer involvement in research and development improves the way research is prioritised. As stated in the foreword to a progress report of this group (Hanley, 1999).

Consumers are the ultimate recipients and beneficiaries of the knowledge derived from research and development. It is therefore not only desirable, but essential that they be involved in developing and implementing strategies for R&D in the NHS.

Non-profit organisations have enabled innovative work and helped service users/survivors gain experience as researchers by funding in-house service user/survivor-led programmes such as the Mental Health Foundation, Strategies for Living (Faulkner and Layzell, 2000), Mind’s Coping with Coming off Psychiatric Drugs (Read, 2005) and Sainsbury Centre for Mental Health’s User-Focussed Monitoring work (Rose, 2001).

TYPES OF RESEARCH

An increasingly empowered citizenship, and consumer movements in every type of public service, along with heightened awareness of the costs of public services, have made governments and public bodies more aware of the need for service improvement, cost-benefit analysis and evaluation, and the political benefits of involving the public in making difficult decisions about resources.

This changed climate, along with the growth of the Consumer/survivor/ex-patient (c/s/x) movements, with their emancipatory outlook, has led to service users being involved in different types of research such as participatory-action research, and evaluation, and in the UK, user-led monitoring. Involvement in ‘pure’ medical research has been a slower process.

US and UK governments, among others, have recently developed policies prioritising evidence-based medicine. As Campbell (Chapter 9) argues, this policy is often worrying to
service users, as it can discriminate against the types of service they value, and against the qualitative research, and small-scale studies where service users are more likely to be involved. The writers in this book explore the power-struggles involved in establishing whose evidence is given the highest priority, the need to re-value qualitative research in mental health, and who should determine outcome measures used in studies (see Chapter 8).

Individual research, e.g personal study, literature reviews, academic theses, published collections of narrative accounts

Amongst these would be included many unpublished, self-published and grey-literature studies such as the aforementioned ECT book by Frank (1978), and books such as those by Susko (1991), Shimrat (1997), Pembroke (1994), Leibrich (1999) which are purposeful, edited collections of service user/survivor narrative accounts. There are many, many more such studies which have provided sustenance for other service users/survivors starting out on similar journeys. Given that most of us started out in our journey to becoming researchers without the tools or the encouragement to do research based on our own life experience, the excavation of narrative accounts has been a pioneering enterprise which is only now becoming academically recognised. Webb (2006) has made a strong academic argument for the validity of first-person research using first-person data on experience (which he argues is only directly available to the subject having those experiences), and first-person methods of analysis, based on phenomenology.

Participatory research, or participatory action research

Van Tosh et al. (2000) looked back on the process of developing participatory research in the USA.

The last decade has witnessed the blossoming of a vibrant consumer research agenda and the growing belief that consumer involvement in research and evaluation holds great promise for system reform, quality improvement, and outcome measurement. The Well-Being Project [1989] made a substantial contribution to understanding the concept of quality of life from the perspective of consumers. Results indicate the validation of personhood, a recognition of common humanity, and a tolerance for individual differences are essential to well-being.

Since then, consumer/survivor researchers in the USA have been involved in evaluation work and have argued for outcome measures based on the values and desired outcomes of service users. A consumer/survivor mental health research and policy-work group worked in the 1990s to develop tools which incorporated the values of recovery, personhood, well-being and liberty (Ralph and Kidder, 2000).

Demonstration, or pilot projects

The purpose of demonstration projects, or pilot projects, is similar to that of action research, to learn about something by trying to put into practice an idea which already has some
evidence base and/or popular force behind it. These are often state-funded ‘experiments’ with new types of service. Russo and Statsny (Chapter 5) refer to the use of demonstration projects as a tool for change in a resistant system. In England (Haigh, 2007; Haigh et al., 2007) service users were involved (to a greater or lesser extent) at all stages, from policy, to implementation, to evaluation, of a Government funded programme which set up 16 pilot projects for people diagnosed with personality disorders.

Involvement in mainstream biomedical research

In the UK, where the Welfare State is still strong, the impact of efforts to control costs along with a stronger voice of patients and consumers of services, has led to national government policy on involving health service consumers. User involvement is a statutory requirement under the Health and Social Care Act 2001, and has now become a requirement of all government-funded research. As a study by Minogue et al. (2003) showed, advocates of involvement believe consumers bring insight and expertise that ‘expert’ professionals do not have, and legitimise and add value to projects. But on the negative side, others expressed concern that

...current legislation and policy, which makes consumer involvement mandatory, could reduce user involvement to political expediency in order to legitimise a research project and any decisions resulting from it.

Government directives in England have led to involvement being a high priority in bodies that receive state funding to support mental health research, such as the Mental Health Research Network, and the Institute of Psychiatry. Rose (Chapter 12) describes one such initiative, the SURE project. Such initiatives can be hard to sustain, given the continuing strength of the biomedical model of mental health, especially where studies are funded by the pharmaceutical industry (see also Chapter 16 by Fisher). Increasing closeness between governments and industry do not bode well for the democratic control of research, and service users/survivors and our allies will have to continue to struggle to move our agenda forwards. Service users have argued that qualitative research is often the best way to study issues of meaning and experience, and should be seen as equal in status with quantitative research in mental health.

LANGUAGE AND TERMINOLOGY

It would not make sense to try to provide a glossary of the terms used in different chapters to describe the subject matter of this book. The language we use in this relatively new academic area is evolving, and each country has its own cultural history of terms and meanings. The best we can attempt is to understand each other’s language and concepts better. Language, beliefs and philosophies are closely interwoven, so until there is common agreement on what is meant by ‘mental illness’ there can be no common language for the related concepts of patients/service users/survivors/consumers, etc. We will however discuss some of the language and terminology issues below.
Evolving terms – ‘mental patient’ to ‘survivor’ and beyond

In the 1980s people on the receiving end of mental health and psychiatric services began to be seen as ‘consumers’ with a right to involvement in their services. This was seen as progressive by some, while others rejected the idea of being consumers. In the UK, an early leader of the service user/survivor movement, Eric Irwin, said ‘mental patients are consumers in the same way that woodlice are consumers of Rentokil’ (personal memory).

The term ‘mental patients’ itself has been owned by some, especially those who were long-stay patients in the old asylums, but this has become increasingly out-of-date now that these hospitals have closed. In the 1980s some people began to term themselves ‘survivors’ (of psychiatry, of services, or of the distress or illness itself). This is still a popular term, though some find it too political or controversial.

In the UK, the term ‘service user’, or ‘mental health service user’ became widely used, as a compromise, though again, many dissented, saying they had not willingly used services. Some preferred the term ‘recipients’ of psychiatric services. In the US activists sought to unite their movement by bringing together the terms consumer/survivor, or consumer/survivor/ex-patient, often shortened to c/s/x.

Another widely-used term in the USA is ‘persons with psychiatric disabilities’. This term makes a strong link with the disability movement and its rights-based agenda and social model of disability, which places the onus on society to end its disabling exclusions.

Finally, many people argue that we are people first and foremost, and should not accept being labelled at all, simply for the convenience of others.

Ultimately, different people will describe themselves differently, and this is as it should be, since our movement stresses the right to self-define.

Models, discourses and worldviews

Service users working inside or outside the establishment do not all share the same perspectives on psychiatry, mental health and mental illness. As Beresford and Wallcraft (1997) argued, there are some who find the social model of disability helpful because of its stress on social oppression and discrimination, while others do not see themselves in terms of disability. Some reject the medical model, with its pathologising of madness, while others accept the concept of mental illness but seek improved treatment with better outcomes. The rise of ‘consumerism’ in health provided an opportunity for involvement, though this has been criticised as a ‘supermarket’ version of choice, not true democratisation based on citizenship and rights.

There are also different views on whether to talk about mainstream psychiatry as a progressive, evolving science, a model, a discourse, or a paradigm. There are similarities between the concepts of models, discourses and worldviews, the main being that one is immediately offered a choice. If current psychiatry can be seen as ‘the medical model’ or the ‘discourse of psychopathology’, or as a ‘eurocentric worldview’ it opens up the possibility of other, very different, ways of seeing and doing things. Many of the chapters in this book refer to these possibilities.
Types of involvement

Several of the chapters look at different types of involvement, such as consultation, collaboration, partnership, and user control of research. These terms may overlap, and in some cases are hotly contentious. For instance, there are different views about whether research carried out within a non-profit organisation by service users can be called ‘user-led’ when service users do not run the organisation.

Terms for those who get involved

The writers have used a number of terms for service users/survivors who are involved in research, reflecting the different roles and different levels of experience that they may have. These include ‘peer specialists’, ‘experts by experience’, ‘service user researchers’, and ‘academic user researchers’. The first two refer to the life experience which is gained by simply being a service user/patient or survivor of mental health services, and the knowledge that has been gained by surviving that experience and from talking to and working with others with similar experiences. Service user researchers are those who bring their personal experience openly to the task of research. Academic user researchers have been defined as those who do the same, but who have research qualifications (see Chapter 15).

The differences in terminology are also a reflection of the emergent nature of these roles. Is there such a creature as a ‘service user researcher’, or should one have the simple status of ‘researcher’? Is a service user researcher of lower status, or does it reflect a new type of research, legitimately and proudly based on personal experience? If so, this new type of research is still nascent. One example might be Webb’s (2006) aforementioned PhD thesis, based on his own experiences of suicide attempts and years of contemplating suicide. His thesis is based on the phenomenological method, with the primary aim being to

\[ \ldots \text{to give voice to the lived experience of suicidality so that it may contribute to a better understanding of the phenomenon. This voice is my own first-person voice, a narrative voice that gives a detailed description of my suicidality as I have lived it and in my own words.} \]

(p23)

The second aim of Webb’s research is to critique of the discipline of suicidology, in which

\[ \text{the first-person, narrative voice [acts] as a prism through which the discipline is viewed to see what this reveals. That is, the formal, disciplinary knowledge of suicidology effectively becomes the ‘data’ of this research and my narrative story the analytical tool. This exercise itself can be seen as a phenomenological reduction that deliberately puts to one side the ‘natural attitude’ of suicidology.} \]

(p23)

The award of PhD for someone arguing a coherent and acceptable academic justification for basing his thesis on his own lived experience, may be an important historic moment for those who have argued that the biomedical discourse of mental illness fails us because it artificially and incorrectly transforms personal experience of distress into categories of ‘diseases’ which assume the appearance of reality only because of the weight of research behind them.
REFERENCES


